

# **The Choices Bank Project**

## **Final Evaluation**

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**The National Telecommunications and Information Administration  
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### I. Introduction

Seriously ill or injured people and the people who make decisions for them are an unrecognized, underserved and vulnerable population. People who have lost the capacity to speak for themselves need others to speak for them. They are surrounded by caring people, but may not receive the care they would have wanted. Families are thrust into decision-making roles that are highly stressful and burdensome. Uncertainty and conflicts within families and between families and health care providers can arise when patients are not able to communicate, and when evidence of their wishes, in the form of advance directives, cannot be found. The emotional pain from this experience can take years for family members to heal.<sup>1</sup>

In response to this problem the Life's End Institute: *Missoula Demonstration Project*, in partnership with eight other organizations<sup>2</sup>, was awarded a grant by the U.S Department of Commerce, National Telecommunications and Information Administration Technology Opportunities Program to initiate the **Choices Bank**.

The public in Missoula County and western Montana was offered their choice of *portals* which accepted completed advance directives for deposit. The staff at these portals was available to provide advance care planning information, review documents for completeness, and transfer them to the data entry site for scanning and entering into the system. The first 22 portals were

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<sup>1</sup>From Contract to Covenant Advance Care Planning Study, funded by the Fan Fox and Leslie R. Samuels Foundation. Missoula Demonstration Project. 2000-2001.

<sup>2</sup> The Choices Bank partner organizations are Life's End Institute: *Missoula Demonstration Project*; St. Patrick Hospital and Health Sciences Center; Community Medical Center Hospital; Western Montana Clinic; Missoula Aging Services; Partners in Home Care; Nightingale Nursing Services; Home Health of Montana; and Christ the King Parish Nurse Program.

located within existing community facilities: the two hospitals in Missoula County, Community Medical Center Hospital and St. Patrick Hospital and Health Sciences Center; the Western Montana Clinic with 15 locations throughout western Montana; Missoula Aging Services, the Missoula area agency on aging; Partners in Home Care, Inc. and its hospice program; Nightingale Nursing Services; Christ the King Church with its active parish nurse program; and the Life's End Institute office. The project trained existing staff within these organizations to serve these portal functions. In years two and three of the project, additional portals were added, including senior centers, a hospice program and assisted living facility in Ravalli County, an attorney's office in Missoula, and the human resource department of Missoula County. People with directives in the Choices Bank were periodically reminded to review them and deposit revised directives through a portal.

## **II. Program Objectives**

This innovative project used Internet-based technology to store 2917 written advance directives (living wills and durable powers of attorney for health care); making them available to authorized individuals at anytime. Targeted individuals for participation in the Choices Bank were those who were over the age of 60 or adult children of parents over the age of 60. The seven specific program objectives were to:

1. Make advance directives accessible to authorized individuals at anytime from anywhere.
2. Increase the efficiency of health care providers and other professionals in locating the advance directives of those they serve
3. Increase the confidence of health care providers and other professionals in patients' and loved ones' abilities to accurately report the existence of a health care advance directive (rather than a financial document)

4. Increase the confidence of patients and designated decision makers that advance directives are always accessible
5. Increase the confidence of designated decision makers that their decision-making authority will be recognized because the advance directive naming them will always be available
6. Increase the number of people with signed advance directives who have discussed their health care choices with key others
7. Meet the needs of its end users by assessing their satisfaction with its services.

### **III. Research Design**

Five major surveys were conducted to evaluate this project (see Appendix A for copies of the surveys). For the depositors, 679 surveys were analyzed at the conclusion of the project, and compared to 586 surveys completed at the beginning of the project. These surveys allowed the staff at LEI to determine the depositors' satisfaction with and confidence in the Choices Bank itself. The return rate of these surveys was 27%. Additionally, 255 health care providers at the partner organizations returned surveys before the Choices Bank project was officially introduced to the public, and 141 health care providers and other professionals returned surveys at the conclusion of the project. These surveys allowed the Life's End Institute to evaluate these health professional's opinions as to how easy the Choices Bank was to use and to assess confidence in its functioning. Finally, 144 designated health care decision makers (out of 232) completed surveys allowing the assessment of their confidence that the advance directives naming them as decision makers were recognized. Information about their levels of satisfaction was also collected. It was not possible to collect baseline information from this group as it was not known they would participate before the project began. In total, these surveys were used to assess the

efficacy of the Life's End Institute (LEI) in meeting its seven major program objectives and corresponding research hypothesis. Each objective and its corresponding research hypothesis will be explored in more detail below.

#### **IV. Evaluation Results**

**Objective 1:** Make advance directives accessible to authorized individuals at anytime from anywhere.

**Hypothesis 1:** The existence and use of the Choices Bank will increase the number of family members and professionals who have access to advanced directives at anytime.

Prior to the development of the Choices Bank, the only Missoula data available regarding advance directives that were accessible 24 hours a day were from LEI's medical chart reviews. Baseline data collected in a 1998-99 Clinical Experience Study indicated that only 30 percent of living wills and only 34 percent of powers of attorney were physically in these charts.

While data that could be used to support Hypothesis 1 was not collected specifically by the research team at LEI, it is true that by March of 2005, **2917** people had deposited or updated advanced directives using the Choices Bank. Also, the very existence of the Choices Bank means that should a person choose to deposit an advanced directive, it would be available 24 hours per day to anyone authorized to access it. Therefore, if the data collected for the Clinical Experience Study can be generalized to the current study, approximately 2042 (70%) of the advance directives deposited by the 2917 depositors would not have been accessible before the Choices Bank Project.

**Objective 2:** Increase the efficiency of health care providers and other professionals in locating the advance directives of those they serve

**Hypothesis 2:** The existence and use of the Choices Bank will increase staff efficiency in

locating advance directives and in assisting people in preparing and revising them.

Prior to the public launching of the Choices Bank, baseline data was collected from 255 attorneys, social workers, chaplains, clinic receptionists, emergency room doctors and critical care nurses at the two Missoula hospitals and 15 Western Montana Clinic sites. This data indicated that 31.8% of these providers did not take steps to find advanced directives for people who were unable to communicate. Only 25% always took steps to find advanced directives. In addition, 64% of the providers were not very confident in the Health Care Advanced Directives when they could find them, probably due to the fact that 67% of the providers had been presented with financial directives when they asked for Health Care Advanced Directives. In addition, 56% of those surveyed only had from 0 – 5 minutes to look at patient files, and an additional 23% were able to add another five minutes. This indicates that providers are very busy and unable to take the time to look beyond the patient files for Health Care Advanced Directives. Similar percentages describe the providers' abilities to take the time to call another organization or to call or contact the family of the patient. If an advanced directive could be found, the average wait was between one and two days for delivery (see Appendix B for the complete frequency distributions for the questions from this survey and the follow-up survey).

This baseline data was compared with data collected from 141 members of this same group (not necessarily the same people) at the conclusion of the project. While the original grant application specified at least four data collection intervals, it was determined during the course of the project that collecting such a large amount of data from already overworked professionals was not good public relations. Therefore it was decided that a simple pre-post project data collection strategy would suffice. In addition, several of the questions from the pre-project survey were changed to allow more specific information to be collected relevant to the Choices

Bank itself. While this data collection strategy does not allow for comparisons to be made on every question, it does allow more useful information to be collected.

The follow-up survey indicated that 62% of the respondents had personally located someone's advance directive using the Choices Bank System. However, 25% of respondents said that if a patient's advanced directive is not stored in the Choices Bank, they would almost never take any steps to find it. Perhaps indirectly, this project has encouraged providers to spend less time looking for Advanced Directives. However, compared with the baseline data, fewer providers admitted to not looking for advanced directives at all, so perhaps the educational component of the Choices Bank Project convinced 5% of these providers of its importance. In terms of the time it takes to use the Choices Bank, the median number of minutes was 10, which interestingly is the maximum amount of time allotted to looking for an advanced directive by 75% of the providers in the baseline survey.

In summary, 46.4% of providers answering the question felt that the Choices Bank was useful to them as professionals, and 59.9% experienced "somewhat" to "extreme" levels of satisfaction. The caveat is that only 97 out of 141 providers answered the questions about usefulness and satisfaction, leaving one to wonder how the other 44 felt at the conclusion of the project.

Comments were collected and analyzed by ratings of satisfaction. Common comments from providers experiencing a low rate of satisfaction were "there is minimal time for these documents" and "it would be better if the connection was a lot faster. It takes forever to look for one on the website". Common comments from providers experiencing a high level of satisfaction were "very helpful to patients to know they have a safe, secure place to keep documents at no cost" and "I work in an ER and it allows me to tailor end-of-life care". The most common

complaint referred to the difficulty some providers had in accessing the Choices Bank (“it’s too difficult to access”). Some providers solved this problem by “calling Med Records to check – they use it more”. It seems that while the service provided by the Choices Bank is valuable to providers and patients, there are some technical issues still to be overcome.

**Objective 3:** Increase the confidence of health care providers and other professionals in patients’ and loved ones’ abilities to accurately report the existence of a health care advance directive (rather than a financial document);

**Hypothesis 3:** The existence and use of the Choices Bank will increase staff assurance that people are accurately reporting the existence of health care planning documents rather than financial planning documents.

The same surveys used for Objective/Hypothesis 2 were used to determine whether Objective 3 was met and Hypothesis 3 was supported. On the baseline survey, 64% of providers were not confident that people were referring to health care and not finances when asked about advanced directives. Sixty-seven percent of providers had been presented with financial documents rather than health care advanced directives when they had asked for health care information. Only 31% of providers had never been presented with a financial advanced directive when they had asked for a health care advanced directive.

In the follow-up survey, the number of providers not confident that people were referring to health care when asked about advanced directives increased to 69.4%. Additionally, the number of providers that had been presented with a financial document when they had asked for a health care advanced directive increased to 70%, a small 3% increase. This could be because the educational component of the Choices Bank Project encouraged providers to ask more detailed questions of the people they worked with, or the small increases could be due to random



error. Either way, it is impossible to conclude that confidence in people's ability to accurately report the existence of health care planning documents as opposed to financial planning documents increased during the duration of the Choices Bank Project.

**Objective 4:** Increase the confidence of patients that advance directives are always accessible.

**Hypothesis 4:** The existence and use of the Choices Bank will increase the confidence of depositors that advance directives will be accessible to them as well as to their designated proxy decision makers, health care providers, and other professionals.

Analysis of two surveys, the depositor survey and the depositor follow-up survey, was required to determine whether Objective 3 was met and Hypothesis 3 was supported. Each will be discussed below. The complete frequency distributions for all of the questions from the surveys are included in Appendix C.

At the time people deposited advance directives in the Choices Bank, they were asked to complete a brief survey. The response rate was 20%, with 589 people answering the questions on the survey. Respondents were first asked questions about demographics. Thirty-four of the respondents were male, 66% were female. Ninety-seven percent of the respondents were Caucasian. Fifty-five percent of the respondents had parents that were 60 years old or older.

Fifty-two percent of respondents indicated that they had previously completed an advanced directive. Thirteen percent of these advanced directives were kept in a safety deposit box, 30% were kept in a desk or file, 16% were kept by the person's designated health care decision maker, 18% were kept by a family member, 2% were kept by a close friend, 17% were kept by the person's doctor, 15% were kept in their hospital medical records, 13% were kept by their lawyer, 2% were kept by the person's faith community, and 3% were kept elsewhere. Only

52% of respondents indicated that they felt confident that these advanced directives could be located. However, after depositing their advanced directives in the Choices Bank, 88% were confident that those authorized could gain access. Therefore, the use of the Choices Bank increased the number of people who felt confident in their ability to find their advanced directives by 36%.

At the end of the project, a follow-up survey was sent to those who consented from the original survey, as well as to those who gave their permission later in the project. Ninety-three percent of the 679 respondents to this survey indicated that they felt confident that their advanced directives could be found at any time when using the Choices Bank. They also indicated that they were very confident that their health care representative, or proxy, could find the advanced directive, as well as any other authorized agent. Compared to the original survey, the number of people who felt confident in their ability to access their advanced directives (either personally or by proxy) increased by 41%. Therefore Objective 4 was met, and Hypothesis 4 was supported.

**Objective 5:** Increase the confidence of designated decision makers that their decision-making authority will be recognized because the advance directive naming them will always be available.

**Hypothesis 5:** The existence and use of the Choices Bank will result in at least 75 percent of proxies reporting confidence that their authority will be recognized because advance directives are accessible.

From depositors who consented, 144 randomly selected proxies or health care representatives were surveyed. The resulting data indicated that 81% of respondents report

“moderate” to “high” levels of confidence that advance directives will be accessible to them, depositors, health care providers and other professionals. Eighty-one percent of respondents felt “moderate” to “extremely” confident that their authority will be recognized by the physician because the advance directive is accessible. Therefore, the hypothesis that at least 75% of proxies will report feeling confident that their authority will be recognized has been supported. Since there was no baseline data on how confident the designated decision makers felt before the Choices Bank, it is impossible to tell if their confidence has increased. However, considering that only 16% of designated health care providers had copies of the advanced directives, it is easy to conclude that proxies or health care representatives probably had very little confidence in their ability to access them before the Choices Bank. One comment from a proxy stated “I know her wishes and how to get a hold of the document easily”. The complete frequency distributions for all of the questions from this survey are included in Appendix D.

**Objective 6:** Increase the number of people with signed advance directives who have discussed their health care choices with key others.

**Hypothesis 6:** The existence and use of the Choices Bank and education materials distributed through its use will result in at least 75 percent of depositors discussing their wishes with their proxies, family members, health care providers or attorneys, and familiarizing them with the Choices Bank and how to access it.

Ninety-two percent of the 679 respondents to the depositor follow-up survey indicated that they have discussed the choices they made in their advanced directive with a family member, 44% with a doctor, PA, or nurse, 35% with friends, 13% with a lawyer, and 12% with clergy. However, only 35% report that they have discussed the choices made in the advanced

directive with their health care representative. Confusingly, 57.9% of the depositors report giving the extra wallet card to their health care representative. This finding is puzzling because one would expect that when the depositor gave their health care representative the wallet card, they would also have discussed their choices. The possibility exists that the depositors were confused by the question, and believed the term “health care representative” to mean something besides their proxy. Or, the depositors simply gave the health care representative the wallet card without explanation. Since 92% of the respondents indicated that they had discussed the choices they made with family members, the 75% goal proposed in the hypothesis was reached. However, it’s not clear how the question was interpreted by the depositors. It may be that depositors did not discuss their choices with their proxies, which would be problematic. However, the more likely interpretation is that the depositors did not understand the question. This is all the more probable considering that 92% of the depositors chose family members as their health care representatives. More specifically, 54.3% of the depositors chose their spouse as their health care representative, and another 37.7 % chose offspring or siblings. The remaining 8.5% chose friends or others as their health care representative. This would indicate that the depositors did discuss their choices with their proxies as well as with other key people.

One way to determine how much the depositors value the Choices Bank and are willing to talk about it is to examine whether the depositors would recommend its use to others. Sixty-two percent of depositors would recommend the Choices Bank to family and friends, 15% to neighbors, 14% to co-workers, and 12% to their health care representatives. While it is encouraging that 62% of the depositors are willing to recommend the Choices Bank to family and friends, their response to this question also calls into doubt their understanding of the term

“health care representative”. It may be that when their proxy or health care representative is a family member or a friend, the respondents fail to identify the family member or friend as their health care representative.

**Objective 7:** Meets the needs of its end users by assessing their satisfaction with its services.

**Hypothesis 7:** At least 75 percent of end users will rate the Choices Bank as very useful and will be very satisfied with the its services.

### **Confidence**

The depositors felt confident in the accessibility of deposited advanced directives. 87.2% of depositors in the baseline survey reported feeling “moderately” to “extremely” confident in the accessibility of their advanced directives using the Choices Bank. Fifty-one percent of these same depositors reported feeling “moderately” to “extremely” confident in the accessibility of their advanced directives before the Choices Bank. At the time of the follow-up survey, 93.1% of respondents reported feeling “moderately” to “extremely” confident in the accessibility of their advanced directives, an increase of 5.9%. This increase could have been due to natural variation in the two samples or to an actual increase in the numbers of people who felt confident in the accessibility of the choices bank over time.

The health care representatives/proxies also felt confident in the accessibility of deposited advanced directives. 83.9% of the proxies surveyed felt “moderately” to “extremely” confident in their ability to access an advanced directive if asked to do so.

### **Ease**

The depositors felt that accessing deposited advanced directives was easy to do.

Specifically, 78.3% of the depositors in the follow-up survey found it “slightly” to “not at all” difficult to access their advanced directives in the Choices Bank. Proxies also felt that the Choices Bank was easy to use. 76.7% of proxies found accessing the Choices Bank to be “somewhat” to “not at all difficult”.

In the baseline survey for the professionals, only 45.9% of respondents “often” to “almost always” found advanced directives in the Choices Bank when instructed to look there. 52.3% of respondents found it “somewhat” to “extremely difficult” to locate someone’s advanced directive in the Choices Bank. In the follow-up survey, only 29% of respondents “often” to “almost always” found advanced directives and 31% said it was “somewhat” to “extremely” difficult to locate someone’s advanced directive using the Choices Bank. Interestingly, while the number of people able to find advanced directives often in the Choices Bank decreased over time, the number of people finding it difficult to find advanced directives using the Choices Bank also decreased. While fewer advanced directives were being found, the Choices Bank became easier to use.

### **Satisfaction**

The depositors were satisfied with the Choices Bank. 91.7% of depositors reported “moderate” to “extreme” satisfaction with the Choices Bank. 86% of proxies felt “moderate” to “extreme” satisfaction. While the professionals were less satisfied, still over half (59.5%) of professionals felt “somewhat” to “extremely” satisfied with the Choices Bank.

### **Usefulness**

Proxies found the Choices Bank to be useful. 76.4% of proxies reported finding the Choices Bank to be “moderately” to “extremely” useful. Professionals found it less useful.

46.4% found the Choices Bank to be “somewhat” to “extremely” useful to them as a professional.

### **Objective/Hypothesis 7 Conclusion**

In conclusion, depositors and proxies reported high levels of satisfaction with the usefulness of the Choices Bank. Professional end users did not find it as useful. In the opinion of the evaluator, this hypothesis was not supported. However, a faster server would result in faster download times for advanced directives. This would likely result in higher levels of satisfaction and perceptions of usefulness among end users (health professionals in particular).

### **V. Summary**

In practice, written advance directives are invaluable to those who must make decisions for another. Advance directives can also serve as a stimulus and guide for discussions, first clarifying the pertinent issues, then conveying the individual’s preferences.

With the passage of the federal Patient Self-Determination Act of 1991, health care providers who receive Medicare reimbursement, including hospitals, nursing homes, home health agencies, and hospice programs are required to ask patients if they have an advance directive. Additionally, the Joint Commission on Accreditation of Healthcare Organizations requires information on the existence of advance directives. These regulations do not address the actual placement of advance directives in a person’s chart. Developing a means to assure accessibility of advance directives is left to the individual institutions. The job of finding patients’ directives regularly falls to social workers and chaplains who, in Missoula, recount time-consuming challenges of hunting for reported advance directives and acquiring a copy if one actually exists. Many people store their directives in locations that are inaccessible in the

evenings, on weekends, or holidays, such as physicians' or attorneys' offices or safe deposit boxes. Others file them in their homes where they may not be found. Similarity of terms for health care planning and financial planning tools add confusion. Health care providers, social workers, and chaplains in Missoula report patients and families commonly provide wills and financial powers of attorney when asked for copies of their *living* wills and powers of attorney *for health care*.

Due to the Choices Bank project, at any time, day or night, a reliable, scanned copy of a person's advance directive was made available to individuals, families, or care providers with Internet access and the necessary security information. Even without Internet access, a distant doctor for an unconscious patient or a frantic loved one could call one of the two hospital emergency departments in Missoula and, with requisite security information, obtain a faxed copy of the advance directive. As patients were transferred between health care facilities, the same, most recently deposited advance directive was available to all simultaneously. As a result, health care providers and staff, including those in emergency departments, were instantly able to check for the most current deposited advance directive to identify their patients' designated proxy decision makers and preferences for health care.

### **Problems**

A small number of problems existed in the implementation of this project as well as the evaluation. Each will be discussed below.

► Some of the survey questions were misinterpreted by the survey recipients. For example, the data indicate that at times, the depositors did not understand who their "health care representative" was. This is a common test construction issue however, and not a major flaw.



► Due to concerns about anonymity, no identifying information was collected from people completing depositor surveys. Therefore, those people could not be contacted for the follow-up, necessitating an entirely new sample.

► Additionally, identifying information such as age of the participant was not collected, eliminating a key demographic analysis. While concerns about protecting the anonymity of the participants are admirable, it is doubted by this evaluator that asking questions related to age or race would have resulted in fewer completed surveys.

► The authors of the grant enthusiastically and unrealistically proposed four evaluation intervals. While proposed in the original grant application, it turned out to be impossible due to the inability of the professionals to participate at such a high level.

► Many of the end-users of the Choices Bank complained of the web-site being slow or hard to understand. Improvements should be made in the networking system capacity and the available bandwidth. This would improve the speed of access resulting in happier end-users who would be more likely to try to access the advanced directives stored in the Choices Bank.

## **Conclusion**

The major success of this project is that the Choices Bank was constructed and used. It now exists, whereas before it did not. The major finding of this study is that depositors like the Choices Bank and appear to benefit from it. They feel confident that their advanced directives will be accessed, and satisfied with the Choices Bank as a whole. Proxies/health care representatives feel confident that their authority will be respected. Providers and professionals report moderate levels of confidence in and satisfaction with the Choices Bank. Overall, this

project was overwhelmingly successful.

The Choices Bank Project serves as a model for other programs nationally. It presents the feasibility of a national database of advanced directives, so that even if a person was traveling to another state and became unable to communicate their health care desires could be known. These findings are presented in the hope that they will be used by government officials with health policy or rural health responsibilities, by hospital administrators deciding where to put matching dollars, by healthcare industry administrators interested in programs that increase customer satisfaction, by aging services providers, and by people interested in peace of mind. The findings from this project should encourage others to expand and improve on these methods. With the deaths of both Terri Schiavo and Pope John Paul II in the collective mind of the public, there has never been a more appropriate time.